Nutrition Resources for People with I/DD

People with I/DD are at greater risk
People with I/DD have an increased risk of having or developing nutrition related problems. This risk can come from an underlying medical syndrome. For example, thyroid conditions are associated with Down Syndrome and can also cause nutritional problems. Or the increased risk can come from physical disabilities/limitations, which predispose individuals to medical conditions such as osteoporosis increasing their risk for fractures. And, limited mobility or physical activity increases the risk for obesity. Many people with I/DD also suffer from dysphagia (difficulties with swallowing) and aspiration of food and drink.

Other conditions commonly found in people with I/DD which impact nutrition include: food allergies or aversions; poor feeding skills; partial or total dependence on enteral or parenteral nutrition; inadequate/excessive energy intake; increased or decreased energy expenditure; thyroid disorders; diabetes; growth alterations (failure to thrive, obesity, growth retardation); metabolic disorders; dyslipidemia; dental issues (missing teeth, caries); reflux (GERD); regurgitation; altered gastrointestinal function; history and/or risk of aspiration; diarrhea; constipation; calcium/vitamin D deficiency; and, medications (anticonvulsants, psychotropic drugs, food-drug interactions, drug-drug interactions) among others.

Helpful Resources
1.) First, start with the provider agency providing services to the individual.
   a) Each agency is responsible for obtaining nutritional services if needed by their client.
   b) Some agencies have registered dietitians on staff (e.g. ARCA).
2) ARCA can also provide nutritional services through secondary freedom of choice (the individual’s right to choose authorized service providers).
3) In the Northeast region contact Sheryl D. Brewer, RD (P.O. Box 90834, Albuquerque NM 87199)
4) Statewide contact the largest provider of nutritional services Global Nutritional Services (GNS) 505-332-8070 (gnsdietitians.com)
5) For children on the medically fragile waiver program, his/her case manager can assist in setting up home based nutritional services.

Most of the time, the dietician can come to the individual’s home and provide individualized medical nutrition therapy, including trainings to the individual, his/her family or team and development of a individualized menu if needed.

The speech language pathologist (SLP) is also an important part of the team to assist in the assessment, diagnosis, and treatment of swallowing disorders.

A copy of Global Nutrition Services’ Tip Sheets on Constipation Prevention Plan; Constipation Treatment for Infants and Children; The Importance of Calcium; The Importance of Calcium to Children; Sources of Dietary Fiber; Nutrition Facts Label; and, Low Fat Cooking Techniques are available on our website: coc.unm.edu/resources/articles.html#GNS
An interview with Carla Fedor, RN CDDN Nurse Manager with CoC, about the Ketogenic Diet Clinic and the Ketogenic diet.

What is the Ketogenic diet?
It’s a diet that is very low in carbohydrates, low in protein and high in fat. The diet consists of foods such as eggs, cheese and meats. It’s an FDA approved treatment for intractable or pharmacoresistant epilepsy.

Is it safe?
Studies have shown that the ketogenic diet is safe when being followed by a team (our clinic has a team consisting of a doctor, a nurse and a dietician). We have found that the side-effects that can be associated with the diet are rare.

Does it work?
We see substantial reduction in the severity and frequency of seizures in about 50% of the people who follow the diet, 10% of people stop having seizures altogether, and 30-40% see a meaningful reduction in either severity or frequency.

Is it hard to stick to?
It can be hard if someone is used to eating mainly carbs and sweets and doesn’t like meat, cheese or eggs. It requires supports from family, friends, school and doctors for someone to follow it over the long term.

How can someone get on the diet?
First, they need a referral from their primary care physician or neurologist. Then they would make an appointment with Alfreda Begaye our clinic coordinator. The clinic occurs once a month. When they come in to see us, we will do an evaluation, explain the diet and make sure it is something that they want to try.

We typically start the patient on the diet in the hospital where we can monitor their labs and educate them and their family regarding the diet. It may take up to 3 months for the benefits of the diet to be fully realized. In situations where the diet is helping, they will stay on the diet for up to three years before we try to wean them off of the diet. During that time, we see the patients every three months to examine them, monitor labs and make sure they aren’t experiencing any problems.

Is it covered by insurance?
Since it is an FDA approved treatment, it is covered. We process the insurance paperwork when they start the diet as an inpatient in the hospital.

Where can I find out more about the diet?
There is a book called “The Ketogenic Diet” by John Freeman that explains the diet in more detail. There is also a lot of information on the internet including the websites of Johns Hopkins, the Charlie Foundation, Epilepsy Foundation and Matthew’s Friends.

The ketogenic diet clinic is a service of the Continuum of Care project. For more information or to make an appointment, please contact Alfreda Begaye at (505) 925-2378. There is also a ketogenic diet clinic booklet which provides more information:
http://coc.unm.edu/clinics/ketogenic.html

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